

## STATE of MINNESOTA

## Proclamation

WHEREAS: Pitt Hopkins Syndrome is a rare and severe neurological disorder caused by a spontaneous

mutation or deletion on the  $18^{th}$  chromosome; and

WHEREAS: Pitt Hopkins Syndrome is characterized by developmental delays, moderate to severe intellectual

disabilities, breathing problems, epilepsy or recurrent seizures, gastrointestinal issues and

distinctive facial features; and

WHEREAS: Approximately 750 people worldwide have been diagnosed with Pitt Hopkins Syndrome, however,

given the fact that the discovery of the gene occurred in 2007, there are likely many other cases that

remain undiagnosed; and

WHEREAS: Given its rarity, online support groups play a pivotal role for individuals, families, and their loved

ones in order to connect and increase awareness; and

WHEREAS: The Pitt Hopkins Research Foundation annually celebrates September 18th as International Pitt

Hopkins Syndrome Awareness Day to raise awareness and funding for Pitt Hopkins research and this date was chosen to bring attention to the fact that it is a disorder caused by a spontaneous

mutation or deletion on the 18th chromosome; and

WHEREAS: The Pitt Hopkins Research Foundation is a volunteer organization of families and professionals

dedicated to finding a cure for Pitt Hopkins Syndrome through the funding of research, education,

and advocacy.

WHEREAS: The Foundation's goal is to bring practical treatment into current medical practice.

NOW, THEREFORE, I, MARK DAYTON, Governor of Minnesota, do hereby proclaim, Tuesday, September 18th as:

## PITT HOPKINS SYNDROME AWARENESS DAY



IN WITNESS WHEREOF, I have hereunto set my hand and caused the Great Seal of the State of Minnesota to be affixed at the State Capitol this  $17^{\rm th}$  day of September.



Pleve Pimm

SECRETARY OF STATE